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Briefing Report to the Chairman,
Subcommittee on Labor, Health and
Human Services, Education, and Related
Agencies, Committee on Appropriations,
U.S. Senate

June 1988

AIDS

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Views on the
Administration's Fiscal
Year 1989 Public
Health Service Budget



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United States
General Accounting Office
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Human Resources Division

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June 2, 1988

The Honorable Lawton Chiles
Chairman, Subcommittee on Labor,
Health and Human Services,
Education, and Related Agencies
Committee on Appropriations
United States Senate

Dear Mr. Chairman:

This briefing report responds to your March 3, 1988, request that we review the proposed Public Health Service (PHS) fiscal year 1989 budget for acquired immunodeficiency syndrome (AIDS) activities. You asked that we explore both the adequacy of the proposed funding levels and the appropriateness of the proposed allocation of funds among these activities. As agreed with your office, we focused on education, patient care, indicators of the spread of AIDS, and limited aspects of the biomedical research components of the budget. On May 26, 1988, we briefed your staff on the results of our work. This report documents and expands on information provided at that briefing.

BACKGROUND

In 1981, the federal budget included \$200,000 for the Centers for Disease Control (CDC) to study AIDS. For fiscal year 1989, the proposed federal PHS budget increased to \$1.3 billion for AIDS to be spent on

- biomedical research to find a vaccine, cure, or improved treatments, \$588 million (45 percent);
- public health control measures to educate the public, \$400 million (31 percent);
- epidemiological studies and surveillance to understand and track the spread of the disease, \$229 million (18 percent) and
- patient care to provide health services to AIDS patients and substance abuse treatment to intravenous drug users, \$68 million (5 percent).



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The budget also contains a \$15 million contingency fund (1 percent) to be used at the discretion of the Assistant Secretary for Health.

The AIDS epidemic is a national public health threat of potentially catastrophic proportions. As of May 1988, CDC reported nearly 61,000 cases of AIDS and about 34,000 deaths since the epidemic began in 1981. PHS predicts that as many as 1.5 million Americans may already be infected with the human immunodeficiency virus (HIV). Epidemiological research suggests that perhaps more than 50 percent of those infected will develop AIDS.

Most of those with AIDS are homosexual men or intravenous drug users. While some contend that the epidemic will continue to be confined to these high-risk groups, in fact, others are also at risk. The size of the future AIDS threat depends upon the current size of the infected population and the rate at which the infection spreads by heterosexual transmission. Epidemiological evidence about the potential spread among heterosexuals neither precludes nor predicts a major epidemic in this population.

Since the development of a vaccine appears to be many years away, federal, state, and local health department officials as well as experts in the research community agree that education is the most powerful public health tool available to reduce the potential impact of the AIDS epidemic. Investing in prevention now can help contain the direct and indirect costs of the disease in the future. As it is, direct medical costs of treating AIDS are projected by CDC to be \$8.5 billion in 1991 (or 1.4 percent of total personal health care expenditures, up from 0.2 percent in 1985). In addition, CDC estimates the indirect costs due to losses in productivity associated with premature death may reach over \$55 billion by 1991. These costs are conservative because they do not include the costs associated with morbidity and premature mortality caused by other HIV-related disease.

The highest numbers of AIDS cases since 1981 are in New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, Georgia, Massachusetts, and the District of Columbia. While two cities--New York City and San Francisco--are currently bearing the brunt of the epidemic, by 1991, 80 percent of the cases are expected to be reported from other areas.

METHODOLOGY

To assess the adequacy of the proposed PHS funding level and the appropriateness of its allocation among various programs, we reviewed recent literature on HIV infection as well as PHS budget documents and also interviewed PHS budget and other federal officials to obtain their views on the proposed budget. In addition, we solicited the views of AIDS experts (see app. II) from the private sector, including advocacy groups concerned about AIDS, and from state and local public health departments with considerable experience with AIDS. In general, these state and local officials are more familiar with the cost of public health efforts aimed at controlling disease and are proponents of increased spending on public health programs in general and on AIDS-related public health activities in particular. We asked these individuals (1) what PHS funding level was needed overall, (2) whether the proposed AIDS budget priorities were appropriate, and (3) how they viewed the proposed AIDS staffing levels and funding mechanisms. GAO did not develop its own funding recommendation but instead reports the views of the experts, which are not necessarily those of the organizations with which these individuals are affiliated.

RESULTS IN BRIEF

The AIDS experts we interviewed recommended that the Congress appropriate more than the Administration has requested for PHS AIDS activities in fiscal year 1989. They proposed budgets ranging from \$1.5 billion to \$2.3 billion, increases of 15 to 77 percent over the Administration's \$1.3 billion budget request. State and local public health officials arrived at a consensus proposal of \$1.7 billion, about 31 percent more than the Administration's budget request. Although both public and private sector experts found the need for all AIDS activities to be compelling, they believe more could be spent in three areas--controlling HIV infection among intravenous drug users, targeting education at high-risk groups, and providing patient care.

We also asked state and local public health officials how they would alter the Administration's allocation of funds if they were constrained to produce a \$1.3 billion budget. They concluded that they would fund increases in the three areas mentioned previously by reducing resources for biomedical research. They reallocated these funds reluctantly, however, and in the unconstrained budget kept biomedical research at the Administration's proposed level. Some private sector

experts and federal officials suggested increasing the biomedical research budget.

The experts told us they might have recommended greater funding increases, but they recognized that lack of trained health care personnel and insufficient facilities limit the amount that can be effectively spent in fiscal year 1989. They believe, however, that building infrastructure would allow the effective use of increased appropriations over the next few years, especially to limit the further spread of HIV infection among intravenous drug users and to provide patient care.

Several of the federal officials and other AIDS experts we interviewed believe that serious staff shortages in PHS may adversely affect management of AIDS programs. Further, they fear that the diversion of staff to AIDS programs is adversely affecting other PHS programs.

The experts also believe that social science research is underfunded and underemphasized in the PHS AIDS budget request. They contend, for instance, that the federal government should make information on program effectiveness available to state and local governments. This would promote channeling of future resources to programs with the most impact on limiting the spread of HIV. In addition, to minimize future treatment costs, they believe that more effort should be devoted to health services research on cost-effective methods of financing and delivering care.

As requested by your office, we did not obtain agency comments on this briefing report. The views of agency officials, however, have been incorporated where appropriate. Unless you publicly announce its contents earlier, we plan no further distribution until 30 days from the report's issue date. At that time, we will send copies to other congressional committees having jurisdiction over the matters discussed in the report, the Secretary of Health and Human Services, and other interested parties.

If you have any questions, please call Sheila Smythe, Chief Health Policy Advisor, at 275-3661.

Sincerely yours,

Lawrence H. Thompson
Lawrence H. Thompson
Assistant Comptroller General

C o n t e n t s

| | <u>Page</u> |
|---|-------------|
| LETTER | 1 |
| INTRODUCTION | 8 |
| Epidemiology of AIDS | 9 |
| Cost of AIDS | 13 |
| Federal Expenditures for AIDS | 16 |
| Objectives, Scope, and Methodology | 19 |
| VIEWS ON THE APPROPRIATE LEVEL AND COMPOSITION OF THE PHS AIDS BUDGET | 21 |
| Experts Recommend More Funds for Drug Treatment, Education, and Patient Care | 21 |
| More Funds Needed to Limit Spread of HIV Infection Among IV Drug Users | 24 |
| More Funds Needed for Targeted Education | 26 |
| More Funds Needed for Patient Care | 29 |
| Evaluation, Surveillance, and Social Science Research Require More Focus | 32 |
| STAFFING AND BUDGETING ISSUES | 36 |
| PHS AIDS Staffing Levels Believed to Be Inadequate | 36 |
| Experts Recommend Continued Separate Funding of PHS Components | 37 |
| SUMMARY | 39 |

Appendix

| | | |
|----|--|----|
| I | FY 89 AIDS Budget Request and Change From Previous Year | 40 |
| II | Members of the GAO Expert Panels | 41 |

Tables

| | | |
|---|---|----|
| 1 | PHS Expenditures and Budgets for AIDS, Fiscal Years 1981-88 | 16 |
| 2 | Estimated Fiscal Year 1988 and Proposed Fiscal Year 1989 PHS AIDS Budgets and Change | 17 |
| 3 | Estimated Federal Expenditures for AIDS by Federal Agencies Other Than From PHS, Fiscal Year 1989 | 18 |
| 4 | State and Local Public Health Officials' Consensus on Constrained and Unconstrained PHS AIDS Budget Functions, Fiscal Year 1989 | 22 |

Figures

| | | |
|---|--|----|
| 1 | Number of Newly Diagnosed AIDS Cases, by Year | 9 |
| 2 | AIDS Routes of Transmission Among Adults and Adolescents | 10 |
| 3 | Distribution of AIDS Cases, by Race and Ethnic Origin | 11 |
| 4 | Ten States With the Greatest Number of AIDS Cases | 12 |
| 5 | States With the Greatest Percentage Increase in AIDS Cases | 13 |

Abbreviations

| | |
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| ADAMHA | Alcohol, Drug Abuse, and Mental Health Administration |
| AIDS | acquired immunodeficiency syndrome |
| AZT | azidothymidine |
| CDC | Centers for Disease Control |
| FDA | Food and Drug Administration |
| HHS | Department of Health and Human Services |
| HIV | human immunodeficiency virus |
| HRSA | Health Resources and Services Administration |
| IOM | Institute of Medicine |
| IV | intravenous |
| NIH | National Institutes of Health |
| OASH | Office of the Assistant Secretary for Health |
| PHS | Public Health Service |

AIDS

Views on the Administration's Fiscal Year 1989 Public Health Service Budget

INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is a fatal disease that severely compromises the human body's ability to fight infections. AIDS is caused by the human immunodeficiency virus (HIV). Although persons infected with HIV may not show any clinical symptoms of AIDS for months or even years, they may remain infected for life and may unknowingly transmit HIV to others. In October 1986, the U.S. Surgeon General reported¹ that AIDS is spread not by casual contact, but primarily through intimate sexual contact and the sharing of hypodermic needles by intravenous (IV) drug users. In addition, infected mothers can transmit the disease to their offspring during pregnancy and delivery or possibly through nursing. AIDS can also be spread via contaminated blood to persons receiving transfusions; however, the risk of getting AIDS from a blood transfusion has been greatly reduced since screening for the presence of the AIDS antibody began in 1985.

Individuals infected with HIV usually produce antibodies to the virus within 6 to 12 weeks of exposure. These antibodies are ineffective in protecting the body from developing AIDS. Presence of antibodies in the blood, or seropositive HIV antibody status, indicates that an individual has been infected with the virus, not that he or she has or will contract AIDS.

The Centers for Disease Control (CDC), a part of the Public Health Service (PHS) within the Department of Health and Human Services (HHS), considers an individual to have AIDS if a blood test indicates the presence of antibodies to the AIDS virus and he or she has one or more debilitating and potentially fatal bacterial, protozoal, or fungal infections. The two most common infections contracted by AIDS patients are pneumocystis carinii pneumonia and Kaposi's sarcoma. Effective September 1987, CDC broadened the definition of AIDS to include two other common AIDS conditions--severe weight loss (wasting) and neurological impairment adversely affecting intellectual capacity (dementia).

CDC has not established a definition of AIDS-related complex, which can also be debilitating or fatal. It is characterized by exposure to HIV and subsequent development of one or more of the following conditions: chronic swollen glands, recurrent fevers, unintentional weight loss, lethargy, and minor alterations of the immune system (less severe than those in patients with AIDS). CDC estimates that there may be eight cases of AIDS-related complex for every case of AIDS.

¹Surgeon General's Report on Acquired Immune Deficiency Syndrome, U.S. Department of Health and Human Services (Washington, D.C.: Oct. 1986), pp. 1-36.

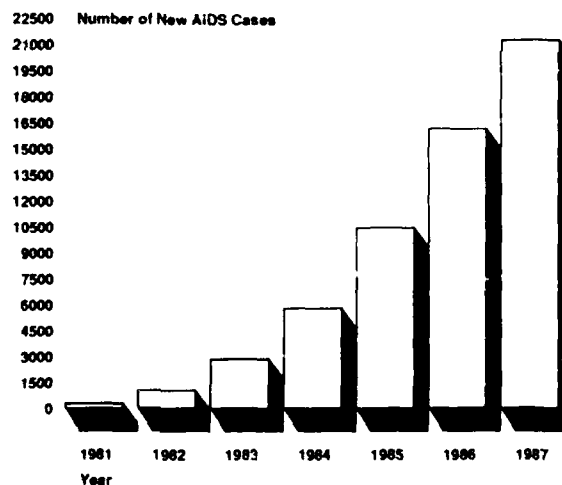
According to the National Academy of Sciences' Institute of Medicine (IOM), a vaccine is not expected to be developed for at least 5 years and probably longer. None of the drug treatments developed so far cures the disease, although at least one, azidothymidine (AZT), prolongs life.

EPIDEMIOLOGY OF AIDS

Epidemiologists identified the first AIDS cases in 1981. By September 1982, CDC had established its definition of AIDS, and a CDC-organized national surveillance system was in place. Since 1983, when most states began reporting AIDS to public health officials, the surveillance system has helped to chart the growing magnitude of the epidemic, delineate its occurrence in major risk groups, and monitor the geographic patterns of the disease.

Since 1981, when about 300 cases of AIDS were reported, the number of reported cases has grown to nearly 61,000. In addition, the number of new AIDS cases reported has increased in every subsequent year, as indicated in figure 1.

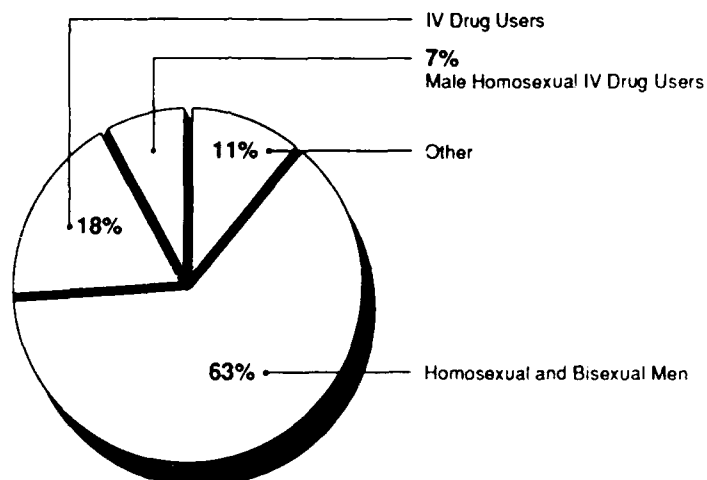
Figure 1: Number of Newly Diagnosed AIDS Cases, by Year



Source: Statistics and Data Management Branch, AIDS Program, CDC

Nearly half the adult reported AIDS cases are in persons aged 30 to 39 years, and 93 percent of reported AIDS cases are among men. As of May 1988, over 34,000 U.S. inhabitants had died of CDC-defined AIDS. As figure 2 shows, most of the AIDS cases as of May 1988 were among homosexual and bisexual men (63 percent), present or past IV drug users (18 percent), and male homosexual IV drug users (7 percent).

Figure 2: AIDS Routes of Transmission among Adults and Adolescents



Note: Other includes heterosexual cases (4.1%), transfusion and blood component cases (2.4%), Hemophilia/coagulation disorder cases (1.0%), and undetermined routes of transmission (3.2%). Percentage totals do not add to 100% because of rounding.

Source: "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Diseases, CDC May 2, 1988

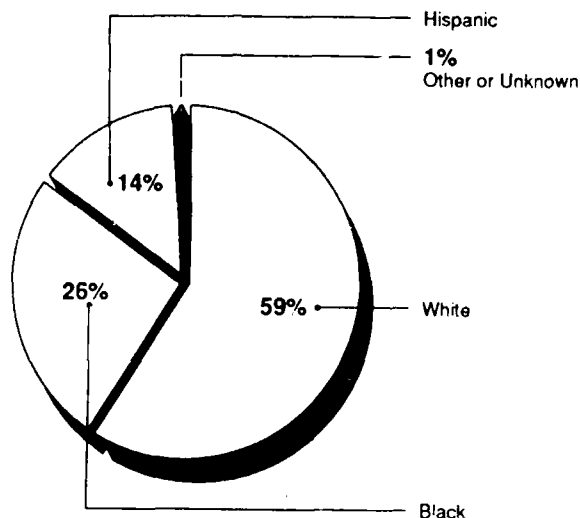
The proportion of AIDS cases among heterosexuals increased slightly from 4.1 percent in May 1987 to about 4.3 percent in May 1988. In 1986, PHS projected the heterosexual caseload would account for 5 percent of all AIDS cases by 1991.

More recent projections of the potential spread of HIV infection among heterosexuals neither predict nor preclude a major epidemic in this population. Using different yet equally reasonable assumptions about key factors, such as the risk of transmission, scientists have predicted epidemics of widely varying severity. All these predictions are consistent with available epidemiological data. Moreover, development of a major heterosexual epidemic cannot be ruled out on the basis of the currently small proportion of

heterosexual cases, even if this caseload remains small for the next several years.²

Figure 3 shows the impact of AIDS by race and ethnic group. As of May 1988, 59 percent of the cases were among whites, but 26 percent were black and 14 percent Hispanic, even though these two groups represent 12 percent and 6 percent of the U.S. population, respectively. The remaining 1 percent represents persons of other or unknown race or ethnic origin.

Figure 3: Distribution of AIDS Cases, by Race and Ethnic Origin (1988)



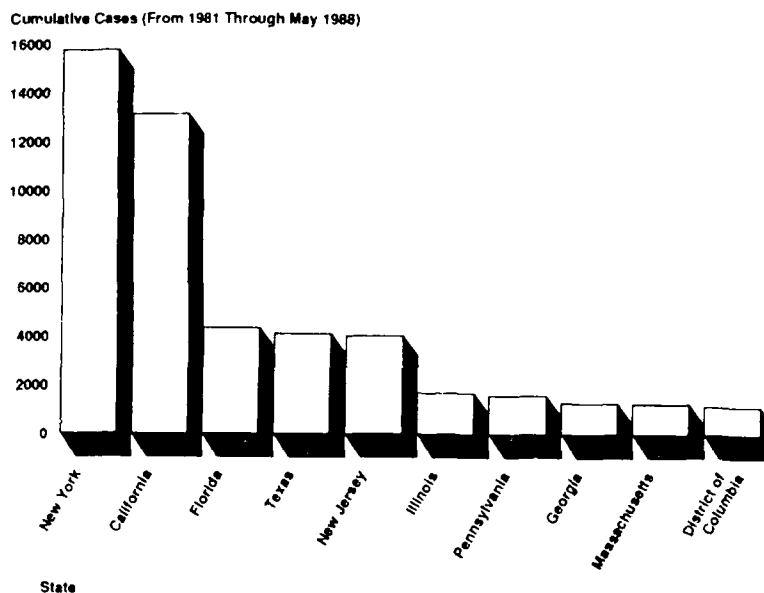
Source: "AIDS Weekly Surveillance Report," Center for Infectious Diseases, CDC, May 2, 1988

Minorities constitute a disproportionate share of the women and children with AIDS. Specifically, 69 percent of women with AIDS are minorities. Moreover, of all AIDS cases in children under 13 years of age at time of diagnosis, 54 percent were black and 22 percent Hispanic. In addition, as of July 6, 1987, of the 410 children born with AIDS, according to a CDC researcher, 73 percent of the AIDS cases were attributed to IV drug-using parents--56 percent from mothers and 17 percent from fathers who passed the virus to the mother, who in turn infected the newborn child.

²DeGruttola, V. and Mayer, K., "Assessing and Modeling Heterosexual Spread of the Human Immunodeficiency Virus in the United States," Reviews of Infectious Diseases, Vol. 10, No. 1 (Jan.-Feb. 1988), pp. 138-150.

From the onset of the epidemic through May 1988, the highest numbers of AIDS cases were reported in New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, Georgia, Massachusetts, and the District of Columbia. (See fig. 4.) Between May 1987 and May 1988, the rate of increase in reported cases in these 10 states ranged from 29 percent in New York to 124 percent in New Jersey. In New York City, AIDS has been the leading cause of death for males aged 30 to 39 years since 1984, and it was reported in August 1987 as the number one killer of females in New York City between the ages of 25 and 34 years.

Figure 4: Ten States With the Greatest Number of AIDS Cases (1988)



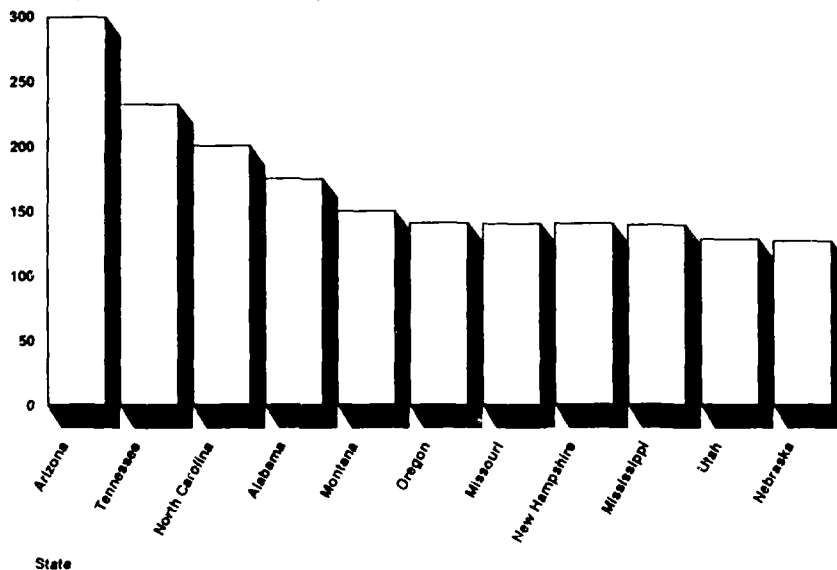
Source: "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Diseases, CDC, May 2, 1988.

CDC data show that HIV infection and AIDS are also increasing rapidly in other states. Figure 5 shows that in states with relatively few AIDS cases (ranging from 18 to 495 cumulative cases), the rate of increase between May 1987 and May 1988 was 175 percent or more in 4 states and exceeded 125 percent in 7 other states. By 1991, PHS expects 80 percent of AIDS cases to occur in areas outside of New York City and San Francisco.³

³PHS expects to update its 1986 projections at a planning conference in June 1988 in Charlottesville, Virginia.

Figure 5: States with the Greatest Percentage Increase in AIDS Cases (1988)

Percentage Increase (From May 1987 to May 1988)



Source: Computed from "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Diseases, CDC, May 2, 1988. Excludes Puerto Rico, which experienced a 507 percent increase in reported cases.

According to IOM, epidemiological and surveillance efforts show that HIV infection is far more common than AIDS. CDC estimates 1 to 1.5 million Americans are infected with HIV. Studies of the prevalence of HIV in blood samples help epidemiologists document HIV's continuing spread in known high-risk groups and help them monitor the potential spread to heterosexuals. By measuring the extent of HIV infection before and after preventive intervention, it may be possible to assess the effectiveness of programs designed to limit its spread. If people reduce the risk of exposure by changing their behavior, for instance, the rate of new infection should be lower.

While infection with HIV does not always lead to AIDS, the probability that it will is not easily dismissed. In 1986, PHS estimated that 20 to 30 percent of those infected might develop AIDS; however, more recent epidemiological research suggests the number that will eventually develop AIDS is more than 50 percent. These percentages do not include the number of persons with AIDS-related complex or other HIV-related disease. Reporting of these cases has not been required, in part because there is no nationally accepted definition to capture the full spectrum of HIV disease.

COST OF AIDS

The cost of treating AIDS varies across the nation. Most studies in the literature have focused on the direct costs

associated with hospitalization. Reports of hospital costs over the lifetime of an AIDS patient have ranged from about \$25,000 to \$147,000.⁴ A review of several studies of the cost of treating AIDS suggests that the lifetime cost of medical care per patient will not exceed \$80,000, an amount comparable to the cost of treating other serious illnesses.⁵

The available studies, however, may understate costs. Because of data limitations, most studies we reviewed exclude the cost of services received outside the hospital, such as drugs, institutional or home-based long-term care, hospice care, ambulatory physician and ancillary services, counseling, and community support services. In addition, such nonacute services are often provided by volunteers and are not included in the cost estimates. As the epidemic spreads to areas where community-based groups are less organized or as the capacity for volunteers to meet the demands of AIDS patients is exhausted, these services will have to be provided in the marketplace or not at all.⁶ Moreover, no estimates of the costs associated with AIDS-related complex or other HIV-related conditions are available.

The most comprehensive and rigorous study of national costs of AIDS was done by Scitovsky and Rice⁷ for CDC. The authors estimated 1986 direct costs for personal medical expenditures at \$1.1 billion and projected that these direct costs would reach \$8.5 billion in 1991. (For comparative purposes, 1991 health costs associated with auto accidents have been estimated by others at \$8.0 billion; digestive cancers, \$4.9 billion; lung cancer, \$3.9 billion; kidney disease, \$3.2 billion; and breast cancer, \$3.1 billion.) These AIDS costs represented 0.2 percent of total personal health care expenditures in 1985, estimated to reach 1.4 percent in 1991. The authors also estimated the indirect costs associated with losses in

⁴Sisk, J. E. "The Costs of AIDS: A Review of the Estimates," Health Affairs, Vol. 6, No. 2 (Summer 1987), pp. 5-21.

⁵Bloom, D. and Carliner, G., "The Economic Impact of AIDS in the United States," Science, Vol. 239, No. 4840 (Feb. 5, 1988), pp. 604-610.

⁶Arno, P. and Hughes, R., "Local Policy Responses to the AIDS Epidemic: New York and San Francisco," New York State Journal of Medicine, Vol. 87 (May 1987), pp. 264-272 and Arno, P., "The Future of Voluntarism and the AIDS Epidemic," presented at a conference on The AIDS Patient--An Action Agenda for New York City (Feb. 25, 1988), pp. 1-16.

⁷Scitovsky, A. and Rice, D., "Estimates of the Direct and Indirect Costs of Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991," Public Health Reports, Vol. 102, No. 1 (Jan.-Feb. 1987), pp. 5-16.

productivity as generally reflecting the premature death of working-age adults. These costs, estimated at nearly \$4 billion in 1985 and \$55.6 billion in 1991, greatly exceed the direct medical costs of treating AIDS.

Although the total direct medical cost of AIDS is still small on a national scale, the epidemic raises financing questions for the entire health care system. First, the distribution of costs is intensely regionalized in those areas of the country with the highest caseloads. Second, the disease so far is prevalent among individuals who are least likely to be insured adequately--the young, minorities, and the poor. As a result, many have noted that the AIDS public policy debate raises generic questions about the role of federal, state, and local governments in providing health care.

Considerable uncertainty surrounds these estimates, however. The key factor is uncertainty about the future course of the epidemic, which makes forecasting future costs extremely difficult. For example, a 1987 study by the Rand Corporation⁸ uses the CDC figures of 220,000 new cases between 1986 and 1991 as a low-range estimate and projects potentially higher caseloads between 400,000 and 750,000 during the same period. On the basis of these prevalence estimates, the study projects treatment costs for the period 1986-91 of nearly \$38 billion. Using the most pessimistic assumptions about increasing prevalence, these cumulative costs could approach \$112 billion.

Two other important variables affect the cost estimates. First, by diagnosis, the distribution of cases of AIDS and AIDS-related complex may change over time. This may raise or lower costs. For example, according to CDC, the proportion of AIDS patients with Kaposi's sarcoma may decrease while pneumocystis carinii pneumonia may increase. Since the latter is more expensive to treat, direct personal medical costs would be expected to rise. Other changes in case-mix may also raise or lower total treatment costs. Second, changes in medical treatment for AIDS, AIDS-related complex, and HIV seropositive but asymptomatic patients are constantly occurring, particularly in high-incidence cities. For example, there is evidence that the average length of hospital stays is declining as outpatient diagnosis and treatment practices develop. Moreover, therapeutic interventions such as AZT affect the costs of treating AIDS in two ways--by raising pharmaceutical costs and by changing the clinical course of the disease. Patients on this drug may live longer but may require a different mix of treatment services. This may in turn raise or lower treatment costs. In addition, drugs such as AZT may improve the quality of life and reduce productivity losses if AIDS patients can continue to work longer than would have been possible without the drug.

⁸Pascal, A., The Costs of Treating AIDS Under Medicaid: 1986-1991 (Santa Monica, Calif.: The Rand Corporation, May 1987).

FEDERAL EXPENDITURES FOR AIDS

Federal spending on AIDS research and prevention has increased dramatically since 1981 when AIDS was first identified. In each fiscal year since 1983, the Congress has increased the AIDS budget by 77 percent to 115 percent over the previous year. Congressional appropriations have consistently exceeded the Administration's budget requests.

Table 1 shows the increase in PHS's annual expenditures from \$200,000 in fiscal year 1981 to \$1.3 billion proposed for fiscal year 1989. In particular, the proposed PHS budget for AIDS expanded funding to six PHS agencies--the National Institutes of Health (NIH); CDC; the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); the Food and Drug Administration (FDA); the Office of the Assistant Secretary for Health (OASH); and the Health Resources and Services Administration (HRSA).

Table 1: PHS Expenditures and Budgets
for AIDS, Fiscal Years 1981-88

Dollars in thousands

| <u>Year</u> | <u>Amount</u> |
|-----------------|---------------|
| 1981 (actual) | \$ 200 |
| 1982 (actual) | 5,555 |
| 1983 (actual) | 28,736 |
| 1984 (actual) | 61,460 |
| 1985 (actual) | 108,618 |
| 1986 (actual) | 233,812 |
| 1987 (actual) | 502,862 |
| 1988 (estimate) | 951,039 |
| 1989 (proposed) | 1,300,000 |

Source: U.S. Congressional Research Service, Federal Funding for AIDS Research (Washington, D.C.: Feb. 2, 1987), p. 9, and PHS fiscal year 1989 budget request.

In recognition of the need for increased funding, the Administration's current fiscal year 1989 budget request for AIDS is almost 37 percent larger than PHS estimated expenditures for fiscal year 1988. Table 2 shows the proposed PHS budget request for fiscal year 1989, broken out by major functions as follows:

- Pathogenesis and Clinical Manifestations: NIH and CDC studies of the origins and nature of the disease, genetic and biological properties of the different strains of the virus, epidemiological studies of risk factors and modes of transmissions, and surveillance to track the spread of AIDS and HIV infection.

- Therapeutics: NIH and FDA studies to support the review of pharmaceutical drugs and biologics to diagnose, care for, and treat patients with AIDS.
- Vaccines: NIH and FDA studies to develop and test antiviral vaccines.
- Public Health Control Measures: CDC and ADAMHA information and education programs encouraging individuals to minimize behavior that may spread HIV infection aimed at the general public, school- and college-aged populations, individuals at increased risk of infection (including minorities and IV drug users), and health care workers.
- Patient Care: HRSA and ADAMHA demonstration projects to determine the best methods of treating AIDS patients and IV drug users.
- Multidisciplinary Research: Biomedical research projects that cut across immunology, virology, and other scientific disciplines; also includes construction costs for biomedical research facilities.
- Contingency Fund: A fund for unanticipated PHS AIDS needs.

Table 2: Estimated Fiscal Year 1988 and Proposed
Fiscal Year 1989 PHS AIDS Budgets and Change

Dollars in millions

| <u>Budget function</u> | <u>FY 1988 estimated</u> | <u>FY 1989 proposed</u> | <u>Change</u> |
|--|------------------------------|-----------------------------|---------------|
| Pathogenesis and Clinical Manifestations | \$276 | \$386 | \$109 |
| Therapeutics | 176 | 243 | 68 |
| Vaccines | 62 | 93 | 30 |
| Public Health Control Measures | 315 | 400 | 85 |
| Patient Care and Health Care Needs | 29 | 68 | 39 |
| Multidisciplinary Research | 92 | 96 | 4 |
| Contingency | 0 | 15 | 15 |
| Total | <u>\$951</u> | <u>\$1,300</u> | <u>\$349</u> |

A more detailed table showing the PHS proposed budget request for fiscal year 1989, by specific budget functions and PHS components, appears in appendix I.

In addition to PHS's funding for AIDS, other federal programs and departments are involved in screening for AIDS, providing medical care to AIDS victims, and paying benefits to people who become eligible because of the disease. AIDS patients may be eligible for Medicaid, a federally aided, state-administered program of medical assistance for low-income persons. They may also qualify for Social Security Disability Insurance, Supplemental Security Income, and Medicare. In addition, the Veterans Administration and the Department of Defense provide medical care to AIDS patients, and the Department of Defense screens personnel and recruits for evidence of AIDS infection.

Other executive branch agencies have also established testing programs. For example, the Department of Labor has a system for screening current Job Corps enrollees and new applicants, the State Department requires testing of Foreign Service employees, and the Department of Justice will support additional testing in a number of state and federal corrections systems. Table 3 shows the approximate amounts to be spent by other agencies in fiscal year 1989 on AIDS.

Table 3: Estimated Expenditures for AIDS by Federal Agencies Other Than PHS, Fiscal Year 1989

Dollars in millions

| <u>Agency and program</u> | <u>Estimated amount</u> |
|---------------------------|-------------------------|
| HHS | |
| Medicaid (federal share) | \$600 |
| Medicare | 25 |
| Social Security | 111 |
| Veterans Administration | 66 |
| Department of Defense | 52 |
| Department of Justice | 6 |
| Department of Labor | 1 |
| State Department | <u>2</u> |
| Total | <u>\$863</u> |

Note: GAO did not verify the accuracy of these estimates.
Source: Public Health Service, HHS, April 1988.

OBJECTIVES, SCOPE, AND METHODOLOGY

On March 3, 1988, the Chairman of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Senate Committee on Appropriations, asked us to review the proposed \$1.3 billion PHS AIDS budget for fiscal year 1989. During discussions with the Chairman's office, we agreed to use a methodology similar to that used for reviewing the proposed PHS AIDS prevention budget for fiscal year 1988.⁹ We agreed to ask AIDS experts to give us their views about (1) what PHS funding level was needed overall, (2) whether the proposed AIDS budget priorities were appropriately set, (3) whether proposed AIDS staffing levels were adequate and (4) what funding mechanisms should be used.

We reviewed recent literature, including IOM's 1986 report on AIDS¹⁰ and the interim report of the President's Commission on HIV infection,¹¹ to update our earlier report and to identify recent developments. We interviewed federal PHS officials to obtain PHS budget justification documents, which we used to develop a summary table and budget synopsis showing proposed outlays by PHS component and AIDS budget function. PHS budget officials agreed that our summary accurately characterized the fiscal year 1989 budget. We also interviewed federal officials at the National Cancer Institute, the National Institute for Allergy and Infectious Diseases, and the National Heart, Lung and Blood Institute--the three National Institutes of Health accounting for most of the NIH AIDS budget.

At the request of the Subcommittee, we contacted selected experts who served on the Committee on a National Strategy for AIDS convened by IOM. We also interviewed experts with state, local, or national perspectives on the budget. By convening panels and interviewing selected individuals (see app. II), we obtained the views of

- private sector experts (providers, insurers, educators, researchers, academics, and advocacy groups) and
- public sector experts (federal, state, and local public health officials)

⁹AIDS Prevention: Views on the Administration's Budget Proposals (GAO/HRD-87-126BR, Aug. 12, 1987).

¹⁰Institute of Medicine, National Academy of Sciences, Confronting AIDS: Directions for Public Health, Health Care, and Research (Washington, D.C.: National Academy Press, 1986).

¹¹Interim Report: Presidential Commission on the Human Immunodeficiency Virus Epidemic (Washington, D.C.: Mar. 15, 1988).

about the level and composition of the funding proposed by the Administration for fiscal year 1989 AIDS activities.

We provided each panel member with the complete PHS budget justification, the GAO synopsis of the PHS budget, and other background information. We asked many of the experts to give us their views on how \$1.3 billion should be allocated over the broad budget categories contained in the PHS budget justification. We also asked for their views on the appropriate level and composition of the overall budget if it were not constrained to be \$1.3 billion.

We asked the panel of state and local public health officials to discuss budget priorities and funding levels and arrive at consensus budget estimates for the \$1.3 billion budget and for an unconstrained budget. We asked the private sector AIDS experts to give us more general views on the appropriateness of the Administration's priorities and funding categories.

GAO did not develop its own funding recommendation but instead is reporting the views of the individual experts we interviewed. These views are not necessarily those of the organizations with which they are affiliated.

Our work was done in April and May 1988. At the request of the Committee, we did not obtain official agency comments. The views of agency officials, however, have been incorporated where appropriate.

VIEWS ON THE APPROPRIATE LEVEL AND
COMPOSITION OF THE PHS AIDS BUDGET

EXPERTS RECOMMEND MORE FUNDS FOR DRUG
TREATMENT, EDUCATION, AND PATIENT CARE

The experts we consulted believe that the proposed PHS budget for AIDS requests funds for all activities essential to deal with the epidemic. From both public and private sector perspectives, however, they identified budget shortfalls in public health control measures and patient care. Although they found the need for all the AIDS activities to be compelling, they emphasized the urgency of reducing the spread of HIV infection among IV drug users, who pose an immediate threat to the heterosexual population at large. They also told us that more money could be effectively spent to educate high-risk groups and to provide patient care.

State and local public health officials submitting estimates of needed funds recommended levels ranging from \$1.5 billion to \$2.1 billion. As a panel, they arrived at a consensus budget that added about \$359 million to the Administration's budget request, bringing the panel's proposed AIDS budget to about \$1.7 billion. Under this budget unconstrained by the Administration's \$1.3 billion limit, the panel held biomedical research--pathogenesis and clinical manifestations, therapeutics, vaccines, and multidisciplinary research--at the Administration's proposed level, but recommended a net increase of about \$193 million to the public health control measures function (see table 4) for information and education efforts. They recommended reduced funding for both general education and development and evaluation of blood tests--a total decrease of \$21 million. They suggested increased funding of \$214 million including

- \$13.5 million for school- and college-aged persons,
- \$15 million for evaluation of information and education efforts,
- \$35.6 million for health care worker education, and
- \$150 million for education targeted at high-risk persons.

They also proposed more than tripling the patient care and health care needs budget function from \$68 million to \$233 million, an increase of \$165 million to include

- \$15 million for AIDS treatment demonstrations,
- \$50 million for the purchase of drugs for AIDS patients, and
- \$100 million for IV substance abuse treatment, irrespective of HIV antibody status.

Table 4: State and Local Public Health Officials'
Consensus on Constrained and Unconstrained
PHS AIDS Budget Functions, Fiscal Year 1989

Dollars in millions

| <u>Budget functions</u> | <u>FY 1989 proposed</u> | <u>Constrained</u> | <u>Unconstrained</u> |
|---|-----------------------------|--------------------|----------------------|
| Pathogenesis and Clinical Manifestations ^b | \$386 | a | \$386 |
| Therapeutics | <u>243</u> | <u>a</u> | <u>243</u> |
| Subtotal (non-additive) | (<u>629</u>) | <u>579</u> | (<u>629</u>) |
| Vaccines | 93 | 93 | 93 |
| Public Health Control Measures ^c | 400 | 434 | 593 |
| Patient Care and Health Care Needs ^d | 68 | 163 | 233 |
| Multidisciplinary Research | 96 | 46 | 96 |
| Contingency | <u>15</u> | <u>0</u> | <u>15</u> |
| Total | <u>\$1,300</u> | <u>\$1,300</u> | <u>\$1,700</u> |

^aIn the constrained budget, the panel could not partition the recommended level (\$579 million) between (1) pathogenesis and clinical manifestations and (2) therapeutics. Without better descriptions of specific research projects and expected payoffs, they suggested reducing the biomedical components of these two budget functions by \$50 million through equal percentage cuts across the board.

^bIncludes epidemiological studies and surveillance.

^cIncludes general information for the public at large and school- and college-aged youths; education, testing and counseling targeted at high-risk groups, including IV drug users; education targeted at health care workers; and development and evaluation of blood tests.

^dIncludes health services for patients with AIDS and substance abuse treatment services for IV drug users, regardless of their HIV antibody status.

Facing the \$1.3 billion budget constraint, state and local public health officials increased funding for public health control measures and patient care and health care needs by reallocating biomedical research, general education, and contingency funds. In considering the proposed funding of biomedical research, the panelists were hampered by the NIH budget being less well-documented than the budgets of other PHS agencies. With their expertise predominantly in public health rather than biomedical research, panelists were uncertain about the consequences of reallocating NIH research funds and were therefore reluctant to advocate strongly such reallocations. In contrast, some private sector experts and federal officials suggested increasing biomedical research funds. Federal officials, for instance, said additional funds could be effectively used to expand clinical trials and to construct specialized containment laboratories for conducting AIDS research.

Private sector experts also recommended a PHS AIDS budget level greater than \$1.3 billion, but, as a panel, neither developed a consensus proposal nor reallocated the \$1.3 billion proposed budget. Although most of these experts did not quantify their views, they provided strong qualitative support based on their program experience for the quantitative increases suggested by other experts. Two private sector experts suggested independently that the budget should be increased to \$2.0 billion and \$2.3 billion. In addition, the private sector panel raised concerns about inadequate access and patient service delivery problems (arising from lack of health insurance in general) and international cooperation on AIDS research. The panel also emphasized the importance of a national plan to conduct research and education campaigns on HIV infection.

Equally important, state and local public health officials said their recommended increases reflected an acknowledgement of capacity constraints (such as not enough trained public health specialists and inadequate facilities), which they contend would limit PHS from spending more resources effectively in fiscal year 1989. Without these constraints, they suggested that they would have recommended higher budgets. They also suggested the rapid development of an infrastructure that would permit the fiscal year 1990 and 1991 budgets to be substantially larger--essentially across the board--than the fiscal year 1989 AIDS budget.

Private sector panelists also believe that incentives exist in the budgeting process for researchers and federal officials to label projects as AIDS-related to enhance the likelihood of obtaining funds. Because of the high level of interest in AIDS, projects that are tangentially related to AIDS may in fact be included in the \$1.3 billion PHS budget request. Although the experts could neither identify nor quantify these projects from the Administration's budget justification, they believe this overstates the PHS dollars devoted to AIDS.

MORE FUNDS NEEDED TO LIMIT
SPREAD OF HIV INFECTION
AMONG IV DRUG USERS

As of May 1988, about 18 percent of all AIDS cases nationally were attributable to needle-sharing by IV drug users, according to CDC. This practice is a source of infection for not only other IV drug users but also their sexual partners and their unborn children. CDC statistics demonstrate the "bridge" between IV drug use and heterosexual AIDS. Approximately 65 percent of heterosexuals with AIDS report having had sex with an IV drug user, and approximately 70 percent of all perinatal HIV transmission is attributable to an IV drug-using parent. The number of IV drug users with AIDS is doubling every 14 to 16 months.

The percentage of AIDS cases related to IV drug use in high-incidence areas, however, varied in 1987 from 30 percent in New York City to 2 percent in Los Angeles. Also, there is considerable geographic variation in the presence of HIV antibody among IV drug users. For instance, data reported by CDC show that in New York City, between 33 and 61 percent of IV drug users tested are positive for HIV antibody; between 24 and 28 percent of IV drug users in Boston tested positive; and generally less than 5 percent of IV drug users tested positive in most areas of the country other than the east coast.

The relatively low prevalence of HIV infection in IV drug users in many parts of the country presents an important opportunity to limit the spread of infection in this high-risk group. Furthermore, since IV drug users are the primary source of transmission of HIV infection to heterosexuals and newborns, containing the epidemic in this group could have a major impact on the projected caseloads in the general population.

Proposed Budget

The proposed PHS budget targets about \$122 million toward IV drug use AIDS-related education activities, up about 64 percent from the fiscal year 1988 level of about \$74 million. The proposed projects include \$20 million for CDC testing and counseling services for IV drug users. The budget also includes about \$65 million for AIDS education targeted at IV drug users, their sexual partners, and health professionals who work with IV drug users. This money is to be administered through ADAMHA's National Institute on Drug Abuse.

AIDS prevention activities for IV drug users include epidemiologic studies and outreach activities to find and educate the sexual partners of IV drug users, as well as studies to measure the prevalence of HIV infection among IV drug users. Other public health control measures include

- a comprehensive community demonstration program to target IV drug users not in treatment and their sexual partners in 15 high-prevalence and 8 low-prevalence cities to demonstrate how to reach, communicate with, and reduce the risk-taking behavior of these individuals;
- a targeted outreach demonstration program to assess the effectiveness of focused strategies to reach high-risk populations;
- Spanish and English instructional videotapes for IV drug users; and
- a drug abuse information and referral hotline.

Expert Views

Private and public sector experts said that additional federal funds for IV drug abuse programs were essential to build more capacity to treat IV drug users. Specifically, the panelists told us that programs to reach and intensively counsel these people must be greatly expanded. Last year, we cited the HIV epidemic among IV drug users as a dangerous and alarming problem because of the potential spread from this group to the heterosexual population at large. The same perception of this threat led the experts to give priority to IV drug users in both high- and low-incidence areas. The Presidential Commission placed a similarly high priority on this problem and recommended that the nation spend \$1.5 billion annually on drug treatment to reach IV drug users.

The potential demand for these programs is large since, according to CDC, only about 15 percent of the estimated 1.1 million IV drug users in the United States are undergoing drug treatment. In addition, many major cities have long waiting lists for treatment slots. Nevertheless, many social, political, and financial barriers preclude rapid expansion of drug treatment programs and other measures aimed at IV drug users. For instance, most communities resist placement of methadone maintenance clinics in their own neighborhoods. While treatment programs for IV drug users would be the preferred option to preventing AIDS, rapid program expansion over the next few years would be difficult for several reasons.

First, current program capacity is grossly inadequate to meet the potential demand. For example, of the estimated 200,000 IV drug users in New York City, only about 35,000 are in methadone or drug-free programs. Furthermore, according to one expert, even if New York City could quadruple its efforts and all IV drug users remained in the programs, 100,000 would still be outside of treatment. Second, program capacity cannot be expanded very rapidly. Specifically, the record rate of addition of treatment slots in New York City was 15,000 over an 18-month period.

Third, these additional slots are expensive--\$30,000 per slot for methadone maintenance and \$80,000 for drug-free treatment. At these costs per slot, the total cost of treating an extra 20,000 IV drug users would range between \$600 million and \$1.6 billion in New York City alone. Although "no frills" methadone programs--those without elaborate mental health and social worker intervention--could cost as little as \$1,500 per case per year, current federal regulations require extensive counseling as an integral part of drug treatment at methadone centers.

In the interim, less expensive methods of reducing the spread of HIV infection that do not require changing drug users' basic behavior, such as teaching drug users how to disinfect needles, could be implemented. Moreover, these methods of prevention can be used for all IV drug users, not just the heroin-injecting population. The 1986 IOM report recognized that not all IV drug users will be persuaded to substitute methadone for heroin or to stop injecting drugs. Therefore, the report recommended experimenting with the removal of legal restrictions on the sale and possession of sterile hypodermic needles and syringes. This would give IV drug users who do not want to enter treatment the opportunity to reduce their risk of acquiring or transmitting AIDS. Several states have attempted to take such action, but they have generally been opposed by law enforcement officials who believe the availability of drug-injecting equipment will lead to more drug use.

The HHS fiscal year 1989 budget proposes increased funding for drug users in low-prevalence areas. As observed by the IOM report, delaying public health education efforts in low-incidence areas until cases occur increases the probability that the AIDS problem in such areas will become much worse. For this reason, the opportunity to forestall the further spread of infection will mean larger expenditures now, but may result in substantially lower treatment expenditures within the next few years.

MORE FUNDS NEEDED FOR TARGETED EDUCATION

Since there is neither a cure nor a vaccine for AIDS, education is the most effective public health tool available to mitigate the spread of HIV infection. In its 1986 report, IOM said that AIDS education should be pursued with a sense of urgency and level of funding that is appropriate for a life-or-death situation.

In the absence of a nationwide, comprehensive education program, the general public has obtained most information on AIDS from the print and broadcast media. An August 1987 survey conducted by the National Center for Health Statistics showed that misunderstandings about transmission persist. For instance, a significant portion (47 percent) of the population believes erroneously that HIV infection is likely transmitted by shared eating utensils; 38 percent, by mosquito bites; 31 percent, by public

toilets; 25 percent, by donating blood; and 21 percent, by working near someone with AIDS.

Federal efforts to educate the public in this area include the October 1986 Surgeon General's Report on AIDS. As of February 1989, about 13.3 million copies of the report had been distributed. In the final fiscal year 1988 appropriations bill, Congress specifically directed CDC to use part of its fiscal year 1988 funds to publish and distribute an AIDS mailer to every American household by June 30, 1988. An 8-page brochure, "Understanding AIDS: A Message from the Surgeon General," was mailed during May and June 1988 to about 108 million households, at an estimated cost of \$17.4 million.

For at least the next several years, the experts believe that education efforts should be intensified, especially those aimed at individuals engaging in behaviors that increase the risk of contracting AIDS. Moreover, education is needed for those who interact personally and professionally with infected persons and for those who are in a position to influence public opinion.

Proposed Budget

The proposed PHS budget for fiscal year 1989 requests about \$374 million for AIDS education and information, up about \$296 million from 1988 funding levels. Efforts in this area would be targeted at four main groups:

- general public (about \$51 million),
- school- and college-aged adolescents and young adults (about \$36 million),
- high-risk and infected persons (about \$242 million), and
- health care workers (about \$44 million).

Expert Views

The 1986 IOM report placed high priority on education. Reflecting on this, one expert who served on IOM's panel observed that the entire \$1.3 billion budget request could be spent on AIDS education alone and that the most immediate return on the investment of public outlays for AIDS would occur there. Other experts supported increased AIDS funding to be used for targeted education. They emphasized that because of cultural and language differences, education programs must be tailored to specific groups at the local level. They also acknowledged the heavy expense associated with targeted education, which requires time-consuming one-on-one communication between trained counselors and at-risk persons.

The experts told us that, given scarce resources, as the epidemic progresses, they would place relatively more importance on

targeting education at specific groups--youth, minorities, and health care workers--and high-risk persons--especially IV drug users. In fact, the state and local public health officials funded more targeted education in part by reducing resources for general education.

Young People

The experts also agreed more funds should be targeted at young people. One private sector expert proposed massive infusion of resources to act as a "firebreak" to limit the threat of HIV infection among young people. One state and local public health panelist said that CDC should expand education for the school-age population and college students by adding possibly 25 staff members to work with the 50 states in implementing strategic and well-defined curricula and developing posters, logos, videos, and other educational materials. For example, a federal information and resource center could provide quality, updated, and tailored health education material and technical assistance to state and local governments and medical providers.

Other experts supported targeting resources to youth but argued that the adolescents at greatest risk of infection are on the streets rather than in schools. These youth will be particularly difficult to reach.

Health care workers

Panelists from the public and private sectors also noted that additional resources are needed to educate health care workers, including physicians, nurses, paramedics, and skilled and lay staff delivering subacute services to allay unfounded fears among health care workers and their families in dealing with AIDS patients. In addition, the literature indicates that some physicians have a profound reluctance to care for patients with AIDS and that a professional ethic to guide physicians in the AIDS epidemic is needed.¹² This situation, if uncorrected, could result in shortages of medical personnel to deal with AIDS patients in the future, according to some experts.

The Presidential Commission noted in its interim report that expert witnesses repeatedly raised concerns about the need for more knowledge about HIV among providers of health care, including physicians, nurses, paramedics, firefighters, and police, and providers of allied health care, such as social workers, therapists, aides, and laboratory personnel. The report emphasized that a well-

¹²Zuger, A. and Miles, S., "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," Journal of the American Medical Association, Vol. 258, No. 14 (Oct. 9, 1987), pp. 1924-1928.

educated health care community is not only vital to the task of caring for the ill but also serves as a role model for the lay public in dealing with the epidemic. During this critical time when substantial fear and misunderstanding about the epidemic exist, leadership from the health care community is crucial to promoting a sense of compassion and rationality among the citizenry, according to the report.

Homosexual Men

One expert stated that homosexual men are an important group for continued preventive efforts for two reasons. First, recent evidence indicates that the highly successful educational programs put in place by the gay community may not be reaching less openly homosexual and bisexual men. Second, the health care community does not know whether the effects of educational programs will endure without regular reinforcement. The expert noted that very little explicit funding in the PHS budget request was targeted at homosexual men.

Minorities

The experts agreed that funding for minorities, who constitute a disproportionate number of AIDS cases, should be increased. One expert suggested increasing minority education efforts from about \$27 million to \$85 million. The experts expressed concern that black and Hispanic communities, particularly in the inner cities, have not been targeted well. They believe that some minorities may be especially hard to reach due to compounding problems such as poverty and poor educational systems. To assure that funds allocated to minorities are used as effectively as possible, the state and local public health officials suggested that the funds be earmarked to

- award grants to service organizations with proven ability to deliver quality programs,
- recruit and train people from particular minority groups who can then become liaisons to their own communities, and
- develop behavior modification methods to reach these population groups.

One panelist also suggested adding funds to recruit minority participants into epidemiological studies and therapeutic drug clinical trials, where they are currently underrepresented.

MORE FUNDS NEEDED FOR PATIENT CARE

For inpatient care alone, current estimates indicate that \$3.5 billion will be expended for 5 million hospital bed days in 1991. AIDS will utilize nearly 2 percent of all medical and surgical beds and account for almost 3 percent of total hospital costs. In areas

of the country where AIDS is most prevalent, these proportions will be much higher.¹³ Other research also indicates that the cost of treating AIDS will profoundly affect major public and private teaching institutions. In particular, public teaching hospitals in states with restrictive Medicaid programs will be most adversely affected.¹⁴

Although the majority of AIDS patients rely on private insurance and their own resources, the disease is also making increasing demands on public sector sources of funding--Medicaid, Medicare, and state and local governments. According to the Health Care Financing Administration, in 1987 Medicaid paid 23 percent of AIDS direct medical expenditures and paid benefits for about 40 percent of AIDS patients. Fiscal year 1989 federal Medicaid spending on AIDS will be about \$600 million, while Medicare outlays will be about \$25 million.

Through HRSA, the federal government has funded demonstration programs to identify alternatives to providing care in inpatient settings for adult and pediatric AIDS patients. These alternatives emphasized home- and community-based alternatives to providing services in a hospital setting. For the purchase of AZT, HRSA distributed \$30 million in supplemental funds, appropriated by the Congress in June 1987, to the 50 states, the District of Columbia, and territories. No estimates of the additional costs of outpatient care, long-term care, and other services for AIDS patients are available. In addition, similar cost estimates for AIDS-related complex and other HIV-related diseases are unavailable.

Proposed Budget

The proposed PHS budget for fiscal year 1989 requests about \$68 million for patient care and health care needs, a proposed increase of about \$39 million over the previous fiscal year's estimated budget. About \$56 million is included for treatment demonstration projects. This amount excludes \$9 million requested for health services research for OASH. HRSA funding, including the treatment demonstrations, would be reduced, however, from about \$26 million in fiscal year 1988 to about \$16 million in fiscal year 1989. This funding supports adult (\$10.7 million) and pediatric (\$5 million) treatment center demonstrations.

¹³Green, J. et al., "Projecting the Impact of AIDS on Hospitals," Health Affairs, Vol. 6, No. 3 (Fall 1987), pp. 19-31.

¹⁴Andrulis, D. et al., "The Provision and Financing of Medical Care for AIDS Patients in U.S. Public and Private Teaching Hospitals," Journal of the American Medical Association, Vol. 258, No. 10, (Sept. 11, 1987), pp. 1,343-1,377.

The proposed budget requests about \$40 million for new ADAMHA treatment demonstration projects and funding grants to states, cities, and other entities to expand drug treatment capacity for IV drug users. About \$3 million is also requested for bioethics and biosafety projects.

Expert Views

The state and local public health officials believe that patient care resources should be supplemented in two areas: (1) services for AIDS and HIV positive persons and (2) drug treatment for IV drug users regardless of their HIV status. When asked how much they would propose spending if there were no constraints on the budget, panelists proposed augmenting funds for patient care and health care needs from the PHS request of about \$68 million to about \$233 million. They suggested that the \$233 million include about \$180 million for AIDS services and drug treatment demonstration projects, \$3 million for bioethics and biosafety (unchanged from the PHS budget request), and \$50 million for purchase of drugs.

Public and private sector experts agreed that while adequate funding for basic research in AIDS prevention and cures must be continued, increased attention should be given to research and demonstrations in the area of health care delivery to AIDS patients, including

- alternative settings for the delivery of care,
- special problems of pediatric AIDS patients,
- case management for AIDS patients,
- effect of AIDS on recruitment and retention of health personnel,
- transitional care for AIDS patients, and
- new methods of reimbursing providers for heavy care patients and for care delivered in alternative settings.

One expert told us that in New York City, AIDS patients on average currently account for about 1,500 hospital beds used daily and that about 40 percent of these patients were in municipal hospitals. It was estimated that AIDS cases will account for 2,700 to 3,000 hospital beds used daily in New York City by 1991. Panelists commented that this situation was resulting in a high financial burden on the hospitals because of uncompensated care.

Panelists also believe that programs to address the emerging pediatric AIDS crisis, including HRSA demonstration projects, are underfunded. In a similar vein, one panelist noted that pilot projects to limit prenatal HIV infection--a rapidly increasing

transmission category--should be given higher priority in the PHS budget. In its interim report, the Presidential Commission found that pediatric AIDS cases (estimated to range from 10,000 to 20,000 cases by 1991) present striking and costly problems for health care and social service systems. HIV-infected babies often live out their brief lives in the hospital at public expense because their mothers may be unable or unwilling to care for them. The Presidential Commission recommended that the federal government spend about \$35 million for foster care and transitional home programs, demonstration projects, and comprehensive outpatient services for children with HIV-related disease.

Some of the experts stated that the PHS budget does not reflect the recent advances in therapeutic treatment, including experimental therapeutics. Specifically, the clinical experience of homosexual white males with AIDS indicates intensive general medical oversight, earlier and more aggressive treatment of opportunistic infection, and more use of experimental treatments. They predict that the standard of practice will continue to change rapidly, especially in the area of ambulatory care. In particular, the prescription of prophylactic drugs for pneumocystis carinii pneumonia is becoming standard medical practice. This may drive up patient care costs and place increasing strains on public payers as the life expectancy of AIDS patients increases and their private resources dwindle.

Last, panelists pointed out that training funds are needed to provide for an adequate supply of trained scientists, physicians, nurses, and other personnel needed to meet future demands of the AIDS epidemic. This need was felt to be especially critical for those trained to do clinical work. Panelists were concerned about the potential shortage of doctors and nurses trained to treat the anticipated large number of AIDS patients.

EVALUATION, SURVEILLANCE,
AND SOCIAL SCIENCE
RESEARCH REQUIRE MORE FOCUS

According to the experts we interviewed, improved federal decisionmaking on AIDS requires placing a higher priority on program evaluation and social science research. These activities require more data collection on the spread of the disease and the ability of the health care system to absorb increasing caseloads. The experts believe that greater emphasis on evaluation and social science research will foster better prevention strategies and public policies to deal with the impact of AIDS on health care financing and delivery.

Evaluation of AIDS Activities Urged

The experts reported that lacking systematic feedback on the results of state and local programs, the health care community tends to rely on anecdotal evidence--an inadequate basis for informed

public policymaking. Citing the experience with the 1960's War on Poverty and the 1970's crash program to combat cancer, the private sector panel contended that continued failure to incorporate explicit planning and evaluation components for both biomedical and social science research would result ultimately in wasted resources. In the current AIDS context, they pointed to the HRSA demonstrations as an example of an area where evaluations were severely underfunded.

Panelists recommended that the federal government take the lead to

- promote a "global" perspective, providing information relevant to the national population, since state and metropolitan governments lack sufficient incentive to do so;
- underscore the importance of independent evaluations, especially those which would pool data from separate programs across like communities;
- emphasize the need to establish goals and measure progress in achieving these goals, such as developing vaccines and other preventive measures; and
- identify and discontinue ineffective preventive approaches and support more promising methods, including programs tailored to meet local needs.

While both the private and public sector panels called for an increase in evaluations of AIDS activities, the state and local officials specifically recommended that \$15 million be devoted to evaluation of education and information efforts.

Weak surveillance system hampers AIDS programs

Data on the full spectrum of HIV morbidity and mortality, which may be available in some states, are not available at the national level. While the states report the number of cases that meet the CDC definition for AIDS, they do not report cases of AIDS-related complex or HIV infection because CDC does not require it. In its 1986 report, IOM recommended that AIDS surveillance be augmented by selective reporting of other stages of HIV infection, such as AIDS-related complex.

According to CDC, lags in reporting AIDS cases have recently increased. In 1987, 80 percent of AIDS cases were reported within 6 months of diagnosis, compared with 83 percent in 1986. More significantly, the average delay between diagnosis and report rose from 3.5 months in 1986 to 4.8 months in 1987. These increased lags may be related to the fact that, in the United States, disease surveillance is largely carried out through "passive" reporting systems. That is, at some point between diagnosis of disease and death, physicians or hospitals send case reports to local or state

health departments which, in turn, report these figures to CDC. The experts cautioned that state and local health departments responsible for data collection are experiencing problems meeting their AIDS surveillance responsibilities.

"Active" reporting systems, which entail state and local health department staff seeking out cases by checking with providers regularly, tend to experience shorter reporting lags than do passive systems and may also provide more complete information. However, experts noted that active reporting consumes more time and is more expensive to operate. In addition, the lack of infrastructure in many locations currently means that start-up costs for active surveillance systems may be high. We were told, however, that for pediatric HIV infection an aggressive active reporting system should be implemented to supplement current procedures, because the underreporting problem may be severe.

Due to reporting lags and other problems with the current surveillance system, adequate surveillance data are lacking to determine baseline infection rates against which the effectiveness of prevention efforts can be measured. A further consequence of inadequate data is that cost estimates of the HIV epidemic can capture only part of the true costs.

The current budget request provides funding for several efforts aimed at constructing a more complete national picture of HIV infection. Specifically, CDC plans to conduct a "family" of special surveys which will expand ongoing surveys of blood samples from selected populations (military recruit applicants, blood donors, prisoners, college students, newborn children, and others). CDC plans to establish a "sentinel" surveillance system in 30 cities at high-risk sites (hospitals, sexually transmitted disease clinics, tuberculosis control clinics, drug abuse treatment centers, and women's health clinics). Although these samples are not unbiased, the experts supported these efforts because they add to the limited stock of health professionals' knowledge about the spread of the AIDS epidemic.

Through the National Center for Health Statistics, CDC is also planning pilot tests this year to determine the feasibility of conducting a random national study of HIV infection. Although in theory this study would provide an unbiased estimate, such an undertaking is fraught with serious methodological obstacles. In particular, the problem of nonresponse threatens the feasibility of such a study. The results of a 1987 survey indicate that 30 percent of the population would not consent to an HIV antibody test as part of a national survey. If pilot studies confirm this nonresponse rate, then continuing this study may not be a wise use of resources.

Social science research lacking

According to the 1986 IOM report on AIDS, the knowledge base in the social sciences needed to conduct evaluations of prevention efforts is rudimentary. The report attributed this to chronic inadequate funding. Seconding the IOM report, the experts told us that more attention to social science research is crucial. In addition, they specifically identified research in the health services area as being needed to strengthen assessments of the effects on the health care system of HIV infection and to guide the development of alternative financing and delivery systems. In particular, studies are needed on (1) the uneven distribution of AIDS costs (both by state and locality and by public and private sources of payment) and (2) the availability of inpatient, outpatient, and long-term care services across the nation.

STAFFING AND BUDGETING ISSUES

PHS AIDS STAFFING LEVELS BELIEVED TO BE INADEQUATE

Several of the AIDS experts and federal officials believe that serious PHS staff shortages may adversely affect management of AIDS programs. There is also concern that diversion of PHS staff to AIDS programs is adversely affecting other PHS programs.

Proposed Budget

The fiscal year 1989 proposed PHS budget requests 1,368 full time equivalent (FTE) employees for AIDS-related activities. This includes 254 FTEs for FDA (an increase of 127), 25 FTEs for HRSA (no increase), 432 FTEs for CDC (an increase of 16), 580 FTEs for NIH (an increase of 70), 57 FTEs for ADAMHA (an increase of 10), and 20 FTEs for OASH (an increase of 20). Costs associated with these FTEs are fully funded in the Administration's proposed \$1.3 billion PHS budget.

Expert Views

Most of the panelists were concerned about AIDS staffing shortages and believed that the transfer of FTEs to AIDS was probably also adversely affecting other PHS efforts. The panelists pointed out that increased AIDS funding for federal programs must be accompanied by sufficient staff to ensure that programs are operated effectively and efficiently. They emphasized the need for an adequate number of project officers to be available to work with grant recipients.

Many panelists feared that CDC was "drastically overreaching," and that staff "burn-out" was likely. They emphasized that state and local health professionals rely on CDC staff and support services. Panelists noted that one of the consequences of the present staffing situation is that the staff have AIDS responsibilities in addition to their existing workloads. This causes conflicting priorities between important missions, such as control of AIDS and other sexually-transmitted diseases.

Panelists believed that CDC is shifting FTEs to AIDS from other areas, which are then adversely affected. State and local public health officials thought CDC needed at least a 20-percent increase in staff just to meet its new, AIDS-related obligatory functions and to adequately direct and monitor its programs. Panelists also criticized the lack of additional FTEs for HRSA and noted ADAMHA's help is needed not only on research but also on service delivery, especially counseling.

The budget request for AIDS activities includes funds for both program activities (extramural research contracts, advertising,

printing, etc.) and staffing (FTEs for intramural research, managing extramural research contracts, and other staff activities). Consequently, assuming a constant staff-grade and pay structure, an increase in FTEs implies, for any given budget level, a reduction in the program activities that can be funded. We did not ask the panel to specify the dollar amount implied by their recommended increases in FTEs or to make tradeoffs between program activities and FTEs. The panel did not provide a comprehensive recommendation for PHS staff levels by PHS organization. To the extent that panelists would not reduce funding for program activities, significant budget increases above the \$1.7 billion consensus budget level would be necessary to fund FTE increases. We did not estimate this amount.

The HHS AIDS coordinator told us that every PHS agency head was concerned about staffing shortages. NIH officials at the National Cancer Institute, the National Institute for Allergy and Infectious Diseases, and the National Heart, Lung and Blood Institute said they needed additional staff to carry out their AIDS research responsibilities above the 70 FTE increase requested in fiscal year 1989. Moreover, they pointed out that even with the requested fiscal year 1989 increase for AIDS, NIH's total staffing has decreased. Specifically, the budget request for NIH for fiscal year 1989 includes a 70 FTE increase for AIDS and a 169 FTE decrease for all other programs--a net decrease of 99.

We did not determine the effect on other NIH programs of shifting FTEs from those programs to AIDS. According to the director of one NIH institute, however, grant awards for other programs were delayed by the need to expedite AIDS grants. We also did not determine whether the additional FTEs for AIDS research represented additional NIH staff or represented a reallocation of existing staff to the AIDS program.

EXPERTS RECOMMEND CONTINUED SEPARATE FUNDING OF PHS COMPONENTS

In fiscal years 1987 and 1988, the Congress funded all PHS programs, projects, and activities through appropriations for individual PHS component organizations. In fiscal year 1988, the Administration requested that the AIDS work of these components be removed from their individual budgets and be funded instead through a single appropriation account, controlled directly by the Assistant Secretary for Health. The Congress chose, however, to continue funding the PHS accounts separately.

For fiscal year 1989, the Administration has again requested that AIDS funds be appropriated in only one account. In addition, the Administration has requested authority to transfer up to 3 percent of the component organization budgets to the AIDS account "as the Secretary deems necessary."

The Administration's rationale for a consolidated account in OASH is threefold. First, the single account will allow PHS to reallocate resources to meet emerging needs (such as testing a new vaccine) with greater ease; second, it will permit greater coordination and communication across the PHS agencies; and third, it will raise the visibility of the AIDS program in the budget process, thus signaling the high priority that the Administration places on fighting AIDS.

We asked the experts for their views on this proposed change in financial control. In general, they opposed centralizing the financial control in OASH at this time. They believe the potential loss of accountability outweighs any potential gains in coordination. Because OASH AIDS personnel have been assigned on a temporary, rotational basis, its AIDS staff has not been permanent.¹⁵ The experts expressed concern that a change in financial control might reduce accountability. They supported making the OASH AIDS staff permanent, developing a strategy for combating AIDS, and creating a strong coordinating and leadership capability.

The panels did not address the matter of transfer authority specifically. In general, they were not opposed to the idea of some flexibility, but they were concerned that resources are already being diverted to fight AIDS from other high priority public health work. Instead of this diversion of resources, they believe AIDS work should be funded with new dollars, thereby increasing the total resources for public health.

NIH officials whom we interviewed reinforced the general thrust of the panelists' comments. While recognizing a consolidated account may have both theoretical and political advantages, most NIH officials interviewed were not persuaded of its desirability on balance. First, they expect consolidation would cause administrative delays in the research funding process. Flexibility would be lost by the individual institutes, which, in order to use or reprogram AIDS funds, would have to request and justify these actions through OASH. Delays and more reporting requirements would ensue. The time needed to initiate the distribution of funds and to adjust program funding through a budget cycle would increase. Second, consolidation would remove from the organization with program management responsibility a program's funding authority. In particular, NIH officials were concerned that, in a consolidated account, the AIDS FTEs would be separated from the funds needed to pay for them. Finally, knowledge that NIH does not control the funds needed to honor these commitments would, it is claimed, generate uncertainty within the research community about funds being available when needed. The same uncertainty would impair the institutes' ability to plan and manage their programs.

¹⁵ According to the AIDS Coordinator, HHS plans to assign 21 permanent staff to the National AIDS Program Office during 1988.

SUMMARY

In summary, we distilled two messages from our discussions with the experts. They suggest that both fiscal and staff resources be increased in fiscal year 1989 and in future years to meet the challenge of reducing the spread of HIV infection. While the range of estimates varied between \$1.5 and \$2.3 billion, the consensus of state and local public health officials was \$1.7 billion, adding about \$400 million to the Administration's budget request. Their increase reflected concerns about budget shortfalls in providing substance abuse treatment for IV drug users, targeted education, and patient care. Both private and public sector experts also expressed concerns about staff shortages and the impact on the management of AIDS programs in PHS.

The experts we interviewed also told us that better data on prevention and patient care should be collected to allocate resources to the most effective preventive efforts and improve financing and delivery of patient care. Faced with an epidemic of potentially catastrophic proportions and rapidly expanding federal funds devoted to preventing AIDS, the experts believe strong federal leadership is needed to ensure cost-effective spending and to limit the spread of the epidemic.

APPENDIX I

APPENDIX I

PT 1989 AIDS BUDGET REQUEST AND CHANGE FROM PREVIOUS YEAR

Aggregate Budget Request
Breakdown by Agency of PT 89 Defr. 1 Request

| | In thousands of dollars | | | | | | | | | |
|---|-------------------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|
| | PT 88 ent | PT 89 ent | PT 88 ent | PT 89 ent | PT 88 ent | PT 89 ent | PT 88 ent | PT 89 ent | PT 88 ent | PT 89 ent |
| Public Health Service | | | | | | | | | | |
| I Pathogenesis & Clinical Manifestations | | | | | | | | | | |
| a Epidemiological Studies | 895,435 | 837,511 | 913,006 | 90 | 80 | 837,532 | 80,000 | 889,129 | 878,540 | 95,315 |
| b Virology | 13,975 | 5,742 | 19,717 | | | | | 19,717 | 5,742 | |
| c Surveillance | 64,067 | 32,411 | 96,478 | | | | | | | |
| d Etiologic Agent and Co-factors | 49,354 | 11,327 | 60,681 | 500 | | 94,700 | 32,100 | 1,718 | 300 | |
| e Immunologic Studies | 32,594 | 18,883 | 42,472 | | | 4,296 | 149 | 33,586 | 6,166 | |
| f Suman AIDS | 9,343 | 4,556 | 13,899 | | | | | 27,531 | 3,545 | |
| g Psychosocial Factors | 11,451 | 7,862 | 19,313 | | | | | 13,899 | 4,556 | |
| subtotal | 276,279 | 169,292 | 385,571 | 500 | 0 | 136,588 | 40,340 | 4,121 | 1,903 | |
| II Therapeutics | | | | | | | | 189,621 | 49,860 | |
| a Studies of Therapeutic Intervention | 146,911 | 54,381 | 201,352 | 18,424 | 7,550 | | | 189,621 | 49,860 | |
| b Drug Purchase & Distribution | 28,756 | 13,136 | 41,892 | | | | | 189,621 | 49,860 | |
| subtotal | 175,127 | 67,517 | 243,244 | 18,424 | 7,550 | | | 41,337 | 13,083 | |
| III Vaccines | | | | | | | | 222,323 | 58,774 | |
| a Development and Evaluation of Vaccine | 62,259 | 30,352 | 92,611 | 12,184 | 3,450 | | | | | |
| subtotal | 62,259 | 30,352 | 92,611 | 12,184 | 3,450 | | | | | |
| IV Public Health Control Measures | | | | | | | | 79,899 | 26,489 | |
| a Information/Education | 296,355 | 71,212 | 373,567 | | | | | | | |
| 1 General Public (non add'l) | 149,548 | 11,239 | 59,785 | | | | | | | |
| 2 School & College Age (non add'l) | 129,318 | 16,534 | 38,450 | | | | | | | |
| 3 High Risk or Infected Persons (non add'l) | 169,525 | 152,445 | 241,910 | | | | | | | |
| 4 Testing, counseling, referral (non add'l) | 172,492 | 138,245 | 192,738 | | | | | | | |
| 5 Health Care Workers (non add'l) | 27,568 | 16,994 | 44,362 | | | | | | | |
| 6 Prevention of Transmission related AIDS | 3,400 | 272 | 3,312 | | | | | | | |
| 7 Development & Evaluation of Blood Tests | 15,358 | 7,262 | 23,218 | | | | | | | |
| subtotal | 315,351 | 84,746 | 408,097 | 9,302 | 4,250 | | | | | |
| V Patient Care & Health Care Needs | | | | | | | | | | |
| a Treatment Demonstration Projects | 26,938 | 37,915 | 64,851 | | | | | | | |
| b Biobank and Bioreactors | 2,282 | 598 | 2,880 | | | | | | | |
| c Drugs | | | | | | | | | | |
| subtotal | 29,218 | 38,513 | 67,731 | | | | | | | |
| VI Multidisciplinary Research | | | | | | | | | | |
| a Construction (non add'l) | 92,205 | 3,541 | 95,746 | | | | | | | |
| subtotal | 92,205 | 3,541 | 95,746 | | | | | | | |
| VII Contingency | | | | | | | | | | |
| subtotal | | | | | | | | | | |
| Totals by Agency | | | | | | | | | | |
| Replaces Full Time Personnel (FTEs) | | | | | | | | | | |
| a This not decrease is the result of non recurring costs of \$15 million for the one time costs during PT 89 | 895,435 | 837,511 | 913,006 | 865,420 | 810,650 | 840,016 | 83,060 | 840,719 | 835,777 | |
| b Personnel costs a non additive item collected from various sources to avoid double counting | 1145 | 273 | 1368 | 254 | 127 | 25 | 0 | 432 | 16 | |
| c In addition, Federal spending for patient care will include about \$600 million to be paid under Medicaid, \$25 million under Medicare, and \$65 million by the Veterans Administration | | | | | | | | | | |
| d This not decrease is the result of non recurring costs of \$15 million for the one time costs during PT 89 | | | | | | | | | | |
| e Personnel costs a non additive item collected from various sources to avoid double counting | | | | | | | | | | |

EXPERTS INTERVIEWED ON THE ADMINISTRATION'S
FISCAL YEAR 1989 PHS AIDS BUDGET

PRIVATE SECTOR EXPERTS

Deborah Cotton, Clinical Director for AIDS, Beth Israel Hospital, Boston, Massachusetts

Leon Eisenberg, Chairman, Department of Social Medicine and Health Policy, Harvard Medical School

Harvey Fineberg, Dean, Harvard School of Public Health

Willis Goldbeck, President, Washington Business Group on Health

Howard Hiatt, Professor of Medicine, Harvard University, Senior Physician, Brigham and Women's Hospital

Shan Haley, Director, State Issues Forum, American Hospital Association

John Henning, Senior Scientist and AIDS Coordinator, American Medical Association

Dorothy Moga, Assistant Vice President, INOVA Health Systems (Home Health and Hospice Perspectives)

Margaret O'Kane, Director of Medical Directors Division, Group Health Association of America

Steven Sieverts, Vice President of Health Care Finances, Blue Cross and Blue Shield of the National Capital Area (Representing Blue Cross and Blue Shield Association)

Mervyn Silverman, Director, AIDS Health Services Program, Robert Wood Johnson Foundation

Gail Wilensky, Vice President, Division of Health Affairs, Project Hope

Jeff Levi, Executive Director, National Gay and Lesbian Task Force

Jean McGuire, Executive Director, AIDS Action Council

STATE AND LOCAL PUBLIC HEALTH OFFICIALS

C. E. Alexander, Chief, Bureau of AIDS and Sexually Transmitted Diseases, Department of Health, Texas

Jeffery Amory, Director, AIDS Office, San Francisco Department of Public Health

David Axelrod, Commissioner of Health, State of New York

Kristine Gebbie, Administrator, Health Division, Oregon

Christine Grant, Deputy Commissioner of Health, State of New Jersey

Stephen C. Joseph, Commissioner of Health, City of New York

Jeanette Restagno, Director, Health Department, Chicago, Illinois

Joyner Sims, AIDS Program Administrator, Department of Health and Rehabilitative Services, Florida

Gillian van Blerk, Director for Health Services, AIDS Administration, Department of Health and Mental Hygiene, Maryland

FEDERAL GOVERNMENT OFFICIALS

Peter Fischinger, Director, National AIDS Program Office, HHS

Daniel Hoth, Director, AIDS Program, National Institute of Allergy and Infectious Diseases, NIH, HHS

Claude Lenfant, Director, National Heart, Lung, and Blood Institute, NIH, HHS

Harrell Little, Chief, Budget Branch, PHS, HHS

Mary Roper, Acting Deputy Director, National Cancer Institute, NIH, HHS

John West, Acting Director, Office of Resource Management, OASH, HHS

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